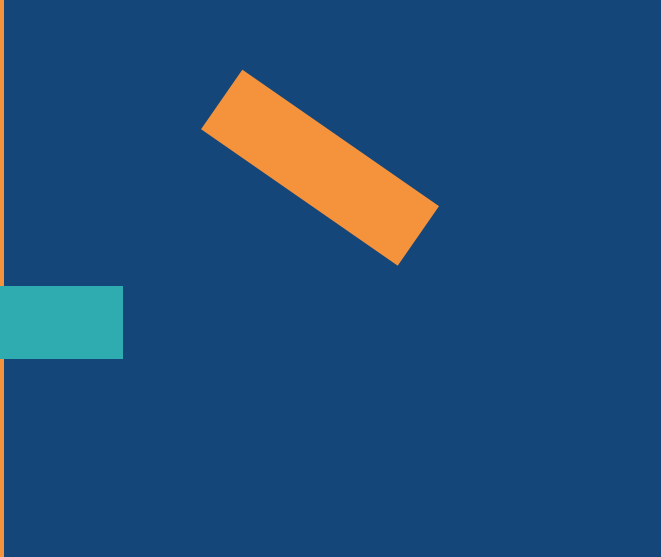
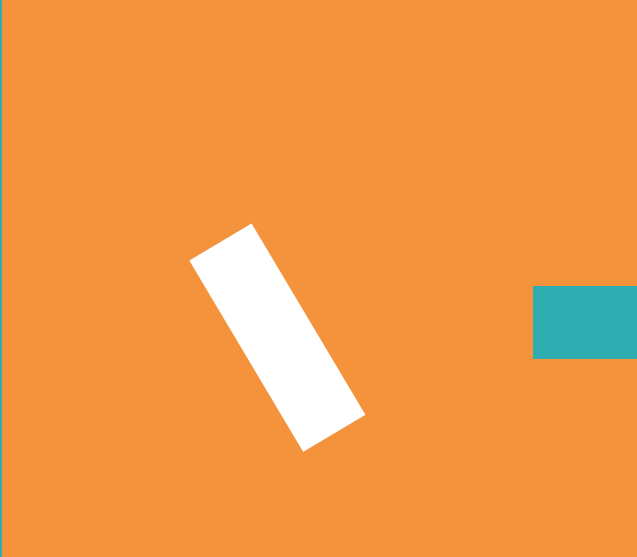
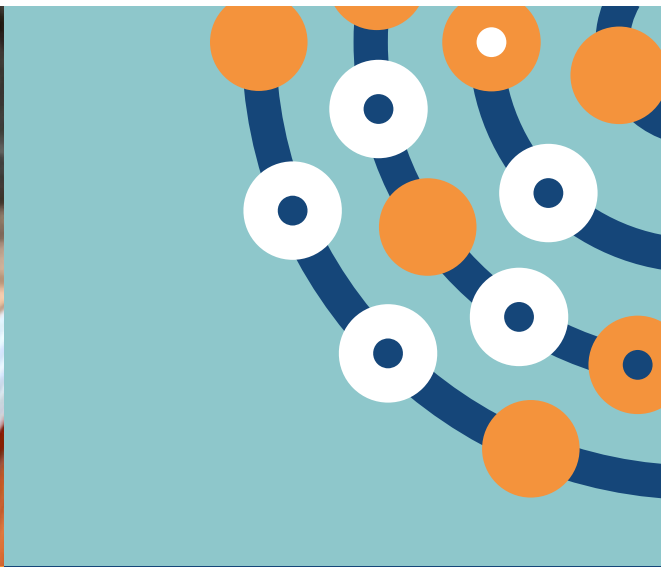


Patient and Public Involvement and Engagement Strategy

2019-24



This strategy highlights our goals and aspirations for public and community involvement, engagement and participation. It also describes the supporting culture, structures and commitments that will ensure that opportunities are neither missed nor mishandled.

This strategy was led and developed by our public and community partners with support from a range of groups and individuals across the Collaboration. It is informed by an evaluation of public involvement in CLAHRC-EM www.clahrce.m.nihr.ac.uk/research/public-involvement-clahrc-east-midlands and should be read in conjunction with the ARC EM PPIE wheel and narrative https://arc-em.nihr.ac.uk/sites/default/files/field/attachment/ARC_Brochure_PPIE_Wheel_0.pdf and PPIE Guidance for researchers <https://arc-em.nihr.ac.uk/resources/ppie-guidance>.

Vision and Aims

We believe that through effective public and community contributions we will be better placed to support the NIHR's aims to promote and protect the interests of patients and the public in health research and, in turn, drive faster translation of scientific discoveries into tangible benefits for patients and act as a sound custodian of public money for the public good.

It is therefore important to us that our public contributors have a strong voice and identity within our Collaboration so that all projects are co-produced by patient and public contributors alongside people from services and academic centres. This will ensure that planning, priority setting and resource allocation for all our programmes is shaped by the needs and views of our diverse communities.

We appreciate the value of bringing non-medical and lay perspectives and contributions to our Collaboration, so that:

- Diverse views inform all study stages from selection to implementation;
- Outcomes that matter most to patients are identified and prioritised;
- Wasteful or unnecessary research is challenged and rejected;
- Participant burden in our research is identified and minimised;
- Communications between researchers and public audiences are clear and open;
- Findings from our publicly-funded studies reach the public quickly and appropriately; and
- Our studies are 'fit-for-purpose' and therefore primed for implementation.

ARC EM has a national leadership role across the ARCs for Equality, Diversity and Inclusion of under-represented Groups. As such, we will collaborate with other ARCs to share best practice and encourage effective community engagement and involvement in as inclusive a way possible to ensure diverse views inform all study stages, as mentioned above, both nationally as well as regionally.

Delivery, Leadership and Reporting

We recognise there are multiple challenges to effective public involvement, engagement and participation and that many communities are poorly represented in health and social care research. For example, the East Midlands includes many of the least well represented ethnic minority groups and CLAHRC EM responded by establishing the Centre for BME Health, to encourage and support contributions from these communities, and which aspired to gain status as a national centre for excellence.

CLAHRC-EM previously had a longstanding Patient and Public Partners' Council (PPPC) that has informed project selection, design, delivery, interpretation and implementation. In ARC EM, the group will become the Community Voices Panel. It will provide a link to the populations we serve, will ensure public influence in all key decisions, and will actively promote co-production. To ensure greater influence and impact, the Community Voices Panel will work closely with the Implementation Hub within the Translating and Implementing Sustainable Service Improvements (TISSI) theme <https://arc-em.nihr.ac.uk/about/our-priorities/translating-and-implementing-sustainable-service-improvement>.

In addition to the Community Voices Panel, the Collaboration will have a range of other structures and groups to promote and support the active involvement of people from diverse backgrounds in our programmes, participation in our projects, and engagement with the evidence we produce:

- A Public Involvement Lead, supported by a PPIE Coordinator will coordinate, facilitate and monitor public involvement, participation and community engagement and will have particular responsibility for championing inclusive practices which will be scrutinised via the Chair of an Equality, Diversity and Inclusion (EDI) group;
- The Ethnicity and Health Inequalities cross-cutting theme will explore issues and promote equality and diversity across projects and programmes, including conducting Equality Impact Assessments on all projects;
- The Centre for Ethnic Health Research <https://ethnichealthresearch.org.uk/> is now an established national centre of excellence and will provide a centralised resource to support those undertaking research and healthcare delivery in partnership with black and minority communities. This will include an extensive training programme, aimed at, but not exclusively for, researchers around effective community engagement, cultural competence and inclusion of under-represented groups in research. In addition, a Community Partners Panel made up of representatives of under-served groups will facilitate engagement and co-production with diverse communities to ensure that diverse voices inform all ARC EM work streams.

To further increase participation from other underserved groups and reduce variations in care, we will make use of new technologies to facilitate involvement, engagement and participation whilst remaining mindful that many of the most socially disadvantaged do not have access to the Internet. We will continue to explore the value of a wide range of digital technologies and media platforms to raise awareness of participation and involvement opportunities to more people, particularly from under-engaged sectors.

We will continue to enact and refresh the commitments to involve and engage members of the public and communities in our structures and activities by the following:

- All Public Involvement activities will be correctly costed in to every research bid proposal
- All groups and meetings will have clear terms of reference and appropriate methods for encouraging and supporting contributions from public members;
- Training in effective involvement, engagement and participation will be available for all those connected with our Collaboration;
- There will be strong public (non-researcher and non-clinical) representation on project steering groups and governance structures;
- Documents and other material intended for general audiences will be reviewed by non-researchers to ensure they are clearly written and appropriately targeted;
- Meetings involving public contributors will be held at accessible times and locations;

Public contributors to groups and committees will be provided with:

- Clear role descriptions which will be regularly reviewed
- Profiles of other members
- A mentor who will support their full and active participation and be available to address issues or concerns
- Training to ensure that they can contribute effectively
- Payment and reimbursement in line with NIHR guidelines 2021 <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>
- Where possible, we will provide opportunities and support for individuals to develop their own project ideas through to fruition;
- We will add to the evidence base for Public Involvement and, particularly, the understanding of the impact of engagement and involvement of under-represented groups and communities;
- We will capture and share best practice, raising the profile of involvement in applied health and care research in an inclusive manner.

Monitoring and Evaluation

In order to provide assurance that PPIE is continually promoted and embedded within all ARC activities there is a continual cycle, ensuring monitoring at all levels within the ARC from individual projects, through Executive Group and up to the Governance Board as described in the PPIE wheel https://arc-em.nihr.ac.uk/sites/default/files/field/attachment/ARC_Brochure_PPIE_Wheel_0.pdf

In addition, the ARC EM evaluation team will develop a 'Meaningful PPI Spectrum' resource to promote effective public involvement and to set out a process for measuring public influence and impact.

The Ethnicity and Health Inequalities Theme will conduct the following study; 'To understand ARC researchers' practices regarding the equality of participant involvement in the planning, delivery, and implementation stages of ARC EM research' <https://arc-em.nihr.ac.uk/research/understanding-arc-researchers-practices-regarding-equality-participant-involvement>.

Our Commitment

ARC EM will provide clear mechanisms and structures, via this strategy, to support engagement and partnership working throughout the research process with particular focus on priority setting and implementing evidence into practice.

We fully support the principles set out in the NIHR report on public involvement, 'Going the Extra Mile' and will enact and be judged by the National Standards for Public Involvement <https://sites.google.com/nihr.ac.uk/pi-standards/home> by offering accessible involvement opportunities that reach people and groups according to research needs.

We will continue valuing all contributions, and building and sustaining mutually respectful and productive relationships, offering support and learning that builds confidence and skills for public involvement in research.

ARC EM will use plain language for timely, two-way and targeted communications and drive improvement by capturing and sharing our experiences of public involvement as well as involving the public in our governance and leadership so that our decisions ultimately promote and protect the public interest.



The National Institute for Health Research (NIHR) Applied Research Collaboration East Midlands (ARC EM) is a partnership between Nottinghamshire Healthcare NHS Foundation Trust and the Universities of Leicester and Nottingham.

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